Acquired Brain Injury Forum for London (ABIL)

Comments on The London Health Inequalities Strategy - draft for public consultation

1. Acquired Brain Injury Forum for London (ABIL)

ABIL is a group of front-line professionals, commissioners, survivors of acquired brain injury (ABI) and carers working to advance the brain injury agenda across London. It was established in March 2007, and currently has 159 members (with a total distribution list of 336). It is concerned with ABI from all causes, both traumatic and non-traumatic (see below). Our new website is at http://www.abilondon.org.uk

2. ABIL recognises that the London Health Inequalities Strategy (HIS) is essentially an overarching strategy, which is not intended to address the needs of specific groups. However, to achieve its aims, it will need to make links with other strategy and policy initiatives within London, and seek to influence their direction and implementation. It is in this context that we set out the case for more-appropriate services for people who have had a brain injury, in the expectation that the HIS can help to influence others - with more-direct responsibility for such matters - to improve such services.

3. ABIL welcomes the draft HIS, which it feels is very much along the right lines, with its emphasis on all Londoners having the opportunity to achieve a good quality of life. In particular, we welcome the reference to:

- the needs of the most disadvantaged, including those with disabilities
- emphasis on the whole person, and the importance of their family and carers
- the need for a fair share of resources for London Health and Social Care Services - including community, preventative and rehabilitation services
- the need for a more equitable allocation of resources, and for access to integrated funding streams where appropriate
- the treatment of mental health - and, we assume, other “non-physical” health conditions - on an equal footing with physical health
- the importance of partnership working across all sectors, including the voluntary and community sector
- for Health and local authorities to work more closely together
- the need to extend opportunities for skill development and progression at work for employees with disabilities; and to increase recognition of the value of unpaid work - including volunteering - both to the community and to the individual’s overall health and wellbeing
- the need for appropriate accessible environments - which we feel could be broadened to include supported living accommodation for people with disabilities

4. Our overall concern, however, is that the kind of initiatives proposed will not adequately meet the needs of people who have had a brain injury unless there is greater recognition of these needs and service providers have the appropriate knowledge and

experience. Knowledgeable provision of this sort is currently very patchy across London - particularly in the community, where it is very much a post-code lottery.

5. Acquired Brain Injury (ABI)

An acquired brain injury is a non-degenerative injury to the brain that has occurred at some point since birth. It can be caused by an external physical force, by disease or by internal physiological events. ABI includes:

- Traumatic Brain Injury (TBI) – which includes open, closed or penetrating head injury – and which can occur as a result of road traffic accidents, sport or leisure pursuits, assaults, falls or battle; and

- Non-Traumatic Brain Injury – which may be caused by: strokes and other vascular events, including subarachnoid haemorrhage; tumours; infectious diseases (eg, encephalitis, meningitis); hypoxia (lack of oxygen), and lack of blood supply, resulting in a brain injury after cardiac arrest; and toxic products taken into the body through inhalation or ingestion, for example due to carbon monoxide poisoning.

6. Effects of Brain Injury on the person and family - a hidden disability

A serious brain injury – from whatever cause – can be life-changing for the individual and their family.

TBI mainly affects young people, particularly in the age range 16 – 29 (and more men than women), whereas stroke affects in the main older people, although, importantly, about 25% will be under 65 and 10% under 50. After TBI (and, for example, encephalitis), the main difficulties usually result from a complex mixture of physical, cognitive, emotional and behavioural problems, and typically a change in personality and a lack of awareness of how the brain injury has affected them.

In many cases after ABI, there is limited physical or sensory disability. The residual effects are largely “hidden”, and thus less easy to observe. This results in misunderstandings, and thus loss of employment, relationship breakdown, low self-esteem, and social isolation for the person, as well as their family. The process of adjustment is very difficult for all. The affected person will in most cases have a normal life expectancy.

Even a ‘mild’ stroke or head injury can in some cases (up to 20%, for the latter) lead to long-term problems.

The needs of brain injury survivors are in many ways different from those with other long term neurological conditions. After the initial acute and post-acute phases, they do not generally have a ‘medical condition’ as such, but rather are left with a range of ‘challenges’ of a psychosocial kind - because of cognitive, behavioural and emotional problems - to which they are trying to adjust and with which they need help from people with knowledge and expertise in the area - and from society at large.

Survivors of a brain injury largely go unrecognised by professionals and the public at large. Although it can have apparent similarities with a number of other conditions - physical disability, learning disabilities, mental health problems, other long term neurological conditions - brain injury needs to be treated as a condition in its own right. Otherwise it will continue to be marginalized and survivors not receive the services they need.

Without appropriate rehabilitation and follow-up support services, they will continue to "fall through the gaps" in service, and are at risk of social isolation, relationship breakdown, homelessness, alcohol and drug dependency, or finding themselves in the criminal justice system. The burden on their families is immense. They represent a significant cost to society. Much of this could be avoided with appropriate and timely interventions.

7. Prevention & contributory factors

A brain injury can happen to anyone at any time.

The wearing of helmets when cycling and undertaking physical sporting activities is known to reduce the extent of brain damage and, in some cases, can save lives.

Alcohol is a major contributor to the occurrence of brain injury. Of equal concern is the high proportion (over 50%) of adolescents and adults hospitalised for traumatic brain injuries who have had pre-injury substance use disorders.

Studies have shown that a significant majority of the prison population have had at least one prior head injury - and often as a child or adolescent.

Work in New York has demonstrated ways in which young people with ABI who were in restrictive settings, including the criminal justice system, could be supported to live in the community - with significant savings to society [#].

8. Recent Government Inquiries in relation to acquired brain injury

There have been a number of initiatives and inquiries in the last decade, but none has led to co-ordinated and prolonged action or any lasting and sustainable improvements across the board.

The two most recent inquiries were:

- The Health Select Committee study 'HEAD INJURY: REHABILITATION' (2001) - which related to TBI http://www.publications.parliament.uk/pa/cm200001/cmselect/cmhealth/307/30702.htm

The Select Committee felt that the subject would have benefited from a wider inquiry by them, but time was not available for this.

- The government's response in 2003 to the Health Select Committee inquiry with the work on the National Service Framework for Long Term Neurological Conditions (NSF), which reported in April 2005 http://www.dh.gov.uk/en/Healthcare/Longtermconditions/Long-TermNeurologicalConditionsNSF/index.htm

Both made very sensible and helpful recommendations, which if properly implemented could have improved the situation to a great extent.

The NSF covered the whole spectrum of long-term neurological conditions - including acquired brain injury from all causes - but had no ring-fenced funding or targets associated

[#] Feeney TJ, Ylvisaker M, Rosen BH, Greene P. Community supports for individuals with challenging behavior after brain injury: an analysis of the New York state behavioral resource project. *J Head Trauma Rehabilitation*. 2001; Feb;16(1):61-75.

with it, and matters were effectively left to local initiatives. We will shortly be half-way through the 10-year implementation period.

There were subsequently a whole raft of government initiatives in the Health and Social Care arena, which have tended to obscure the issue as far as long term neurological conditions (LTNC) are concerned. The general inability of Health and Social Services to work together in an integrated way, as suggested in the NSF, has continued to cause problems for people who have had a brain injury.

9. Extent of ABI (and some economic implications)

Most is known about the numbers of people with TBI and stroke. According to the NSF for Long Term Neurological Conditions (NSF) (2005) and the National Stroke Strategy (2007):

- about 8000 people of working age are hospitalised in London with a TBI each year
- a much larger number (ca. 130,000 in London) attend A & E each year, with post-concussion syndrome (very short or no period of unconsciousness) – so-called 'mild TBI')
- about 3000-3500 people under 65 (approx 1000 under 50) suffer a stroke each year in London
- there are approx 55,000 people of working age living with the long-term effects of a TBI in London (there are no comparable estimates for stroke or other forms of ABI)

Not only the personal but also the economic consequences of ABI are enormous. In the UK the annual costs of direct and informal care and lost productivity after stroke have recently been estimated at £7 billion. Similar data describing the overall economic burden of TBI in the UK are not available, but the cost must be of similar magnitude as that of stroke as it has been estimated to be about $60 billion annually in the USA *.

There is evidence that providing the right rehabilitation and support at the right time can result in substantial cost savings – but this often means spending money in one area to provide greater savings in another. Two obvious examples are:

- if people who have had a mild-to-moderate brain injury can be helped to retain their existing job or return to paid work in some other way, the savings to the exchequer will by far outweigh the cost of the interventions.
- If people who would otherwise find themselves in the criminal justice system can be supported to live in the community, the cost savings will be substantial.

10. Rehabilitation and support needs after ABI

To achieve the best level of recovery, people will need specialist rehabilitation and support services across the whole care pathway – both as an inpatient and in the community.

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* Department of Health. Reducing Brain Damage: faster access to better stroke care'. National Audit Office, London, 2005.
Thurman D. The epidemiology and economics of head trauma. In *Head Trauma: Basic, Preclinical, and Clinical Directions.* Miller L, Hayes R, eds. New York, NY: John Wiley & Sons, 2001.
Finkelstein E, Corso PS, Miller TR. The incidence and economic burden of injuries in the United States. New York, NY: Oxford University Press, 2006.

With the right interventions – and, importantly, long-term follow-up support and encouragement – the person can be helped to be as independent as possible, and to have a good quality of life.

Currently there are shortages of provision – in terms of expertise and capacity – in rehabilitation at all levels, and a lack of recognition that impairments following brain injury often require long-term support.

A general assessment of the current situation in London is given in the Appendix.

11. The London Health Inequalities Strategy (implications for ABI)

ABIL welcomes the HIS as an overarching plan to improve the health and wellbeing of all Londoners. As regards people who have had a brain injury, we would like to see the strategy make links with other bodies within London with more-direct responsibility for such matters, who through their policy actions can improve services for this group of people (such as the NHS in London, Association of Directors of Social Services, the DWP). In particular, we would like to see:

- A greater understanding by Health and Social Care and other professionals in London of the effects of brain injury and the needs of survivors and families/carers;
- A review of rehabilitation services for ABI across London, with the aim of ensuring equality of access to services across the whole care pathway; and in particular to knowledgeable, interdisciplinary community rehabilitation services, close to where they live, for people who have had a brain injury;
- Equality of access to knowledgeable follow-on support in the community – through Social Services and the voluntary sector – to sustain and build upon the rehabilitation gains made and aid the re-integration of survivors into the community;
- The provision where appropriate of supported living accommodation for people who have had a brain injury;
- Further investment in supporting ongoing community services provided by the voluntary sector such as Headway;
- Health and Local Authorities working in an integrated way to provide services to people who have had a brain injury;
- The development of services to help people after a brain injury to return to productive activity – to paid employment or other occupational pursuits which benefit the local community. This will need both specialist vocational rehabilitation services and others with suitable knowledge, together with a change in attitude of employers and other people in the community.

9th January 2010

Appendix

Rehabilitation and support needs after ABI - current situation in London

Acute services

ABIL welcomed the Healthcare for London plans - as part of the Major Trauma initiative - as representing improved services at the acute stage, which should lead to reduced mortality and better initial outcomes for survivors of TBI (either isolated brain injury or as part of polytrauma), who constitute about 60% of major trauma patients. This will include a period of acute rehabilitation, and the services of a 'navigator' to guide the person/family regarding the necessary follow-on phases and to facilitate transitions between services.

However, in our response during the Major Trauma consultation process, we voiced serious concern that, unless the necessary follow-on rehabilitation and support was also provided, the excellent rapid response and acute treatment being implemented would be severely compromised, both as regards the long-term cost-effectiveness of the initial response and the quality of life of the survivors and their family and carers.

Specialised inpatient neurological rehabilitation – the pan-London specialised neuro-rehabilitation consortium commissions services across London, at present via nine specialist providers. This aims to provide equity of access across London. However, there are some capacity issues and thus waiting times can be too long; there is geographical variation, with different providers having different skills/expertise; and timely and appropriate discharge can on occasion be a problem.

Specialist community neurological rehabilitation and follow-on support – although there are some very good services available, provision varies markedly across London.

Some PCTs have local multi- or inter-disciplinary teams which may include specialist physiotherapy, occupational therapy (OT), speech & language therapy (S & LT) and neuropsychology. Others have more-general community rehabilitation services - which, for brain injury, will need ongoing support and guidance from a specialist regional outreach team. Some PCTs have no community rehabilitation service, in which case people may be referred to a specialist regional outreach team; the amount of intervention these teams can provide, and the extent of any follow-on services, are often limited. Some people receive nothing. It's very much a post-code lottery.

There is also an acute shortage of clinical neuropsychologists working in the community - their input can be particularly important in helping people with the very difficult process of adjustment after brain injury.

Specialist Vocational (work) rehabilitation services

Returning to work is very important for people after a brain injury, either to their previous employment or, if this is not possible, in some other form of productive activity, It provides opportunities to re-build self esteem and re-integrate into society, as well as the more obvious potential financial benefits. In order to achieve this, there is often a need for specialist brain injury vocational rehabilitation services, since the more-general, mainstream providers do not have sufficient expertise and understanding of the effects of ABI to work effectively with this client group.

In some areas, community teams and Headway Centres in London provide some vocational/occupational rehabilitation, or prepare people to engage in more specialist

vocational rehabilitation. However there is currently only one specialist brain injury vocational rehabilitation service in London. There is also, of course, a need to educate employers and colleges about the needs of this group, particularly their cognitive and behavioural needs.

Headway East London is at the early stages of an innovative project - 'The Discovery Programme' – the aim of which is for people who have had a brain injury to establish community-based projects which use their skills – in partnership with others - to benefit the wider community.

Follow-on support in the community

This should be as specialised and informed as rehabilitative care, to enable brain injured people to maintain and consolidate rehabilitation gains made, and live a meaningful life in the community. This will in particular involve support through local Social Services and from Headway and other voluntary sector organisations, such as Different Strokes, in London.

Headway provides important social rehabilitation and long-term peer support to survivors and carers and family members. There is a significant lack of capacity in terms of Headway support services in London – with only two major Headway centres, two other groups providing some daytime services, and two others providing monthly evening support services (including some for carers). Links to Headway groups in London can be found at http://www.headway.org.uk/Regions/London.aspx.

There is also a need for supported accommodation for some people - with support onsite or otherwise readily available. This would be a partnership between Local Authority Housing and Social Services, and possibly the voluntary or private sectors.

Action

In our response during the Major Trauma consultation process, we suggested that the whole area of rehabilitation and support for brain injury survivors should be addressed in a co-ordinated and integrated way on a pan-London basis by Health & Local Authorities working together, and involving other agencies, such as DWP and the voluntary and private sectors. There should be a thorough review covering what currently exists in London - and how well it is working - and of effective services in other parts of the UK and abroad.

In the recent report of the Health Gateway Review of the Major Trauma Project, carried out in September 2009, the following recommendation was made:

"There is a general recognition that the availability of good rehabilitation services is an integral component of maximising the benefits of improved trauma care for patients. There is an acknowledgement that these are not in place in London. We recommend that a pan-London strategy be developed for rehabilitation which ensures patient specific treatment pathways, demands more flexibility from existing service providers and commissions a multiple needs service."